



New Health Guidelines Released

Diagnosis, Surveillance and Management of Rare Genetic Disease Tuberous Sclerosis Complex

Pediatric Neurology: Two Peer-Reviewed TSC Papers Featured October, 2013

For more details about the new TSC clinical consensus guidelines, please visit www.tscanada.ca

TSC Canada is pleased to announce newly updated clinical consensus guidelines for the diagnosis, surveillance and management of tuberous sclerosis complex (TSC). Available free of charge, papers detailing the guidelines are available, with open access, to anyone in the world.

TSCanadaST encourages patients and caregivers to share these articles, linked to our website along with summary documents, with their healthcare providers, including family doctors and specialists. Any future updates to these recommendations will also be posted on our website under *Resources: New International Consensus Guidelines for TSC Diagnosis and Treatment.*

To communicate the recommendations to healthcare professionals, the October issue of *Pediatric Neurology* includes two peer-reviewed papers detailing the new guidelines – one entitled “Tuberous Sclerosis Complex Diagnostic Criteria Update: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference” and the other, “Tuberous Sclerosis Complex Surveillance and Management: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference.”

Darcy A. Krueger, MD, PhD, of Cincinnati Children’s Hospital Medical Center, and Hope Northrup, MD, of The University of Texas Medical School at Houston, each wrote the papers in *Pediatric Neurology*. Drs. Krueger and Northrup served as co-chairs of the TS Alliance’s 2012 International TSC Consensus Conference.

The conference involved 79 TSC experts from 14 countries to develop the new guidelines, including TSCanada Medical Advisor Dr. Ute Bartels, neuro-oncologist at the Hospital for Sick Children in Toronto. Dr. Bartels states: “I firmly believe that these recommendations provide essential insight into a complex disease and will contribute to improved comprehensive care throughout an individual’s lifetime.”

Because TSC involves multiple bodily systems, the conference included specialists in genetics, neurology, epilepsy, cardiology, neurodevelopment and behaviour, dermatology, dentistry, nephrology, pulmonology, ophthalmology, gastroenterology, endocrinology and others.

“These two consensus papers will help to guide our diagnosis and management strategies for TSC until enough additional information accumulates to justify the next revision,” comments E. Steve Roach, MD, Editor-in-Chief, *Pediatric Neurology*.

Tuberous sclerosis complex is a genetic disease affecting over 3500 people in Canada and more than 1 million worldwide. It causes tumours to form in vital organs, primarily the brain, heart, kidneys, skin, eyes, liver and lungs. TSC is also the leading genetic disorder associated with epilepsy and autism. Currently, there is no cure.

According to Dr. Krueger, “TSC’s manifestations vary widely among individuals and can sometimes even be life threatening, so accurate clinical consensus guidelines are critical to ensure optimal healthcare management. We are thankful to everyone who worked so hard at the 2012 conference.”

“Gathering so many experts was crucial to ensure the updated recommendations benefited from a wide range of diverse perspectives,” added Dr. Northrup. “Moreover, rapid advances are occurring in TSC treatment research, so we are excited about the new focus on the importance of comprehensive and coordinated care outlined in the guidelines.”

TSCanada Medical Advisor Dr. York Pei, nephrologist and Head of the new Adult TSC Clinic at Toronto General Hospital, welcomed the new consensus guidelines, adding that “these will greatly facilitate the standardization and optimization of TSC patient care.”

According to TSCanada Medical Advisor Dr. Philippe Major, Director of the TSC clinic at the CHU Sainte-Justine, University of Montreal, “These new guidelines for the diagnosis and management reflect the advances recently made in the field of TSC. It reinforces the need for coordinated care and constant surveillance in order to make sure that people living with TSC remain as healthy as possible.”

TSCanada Director Patricia Nolan, a member of the TSC International (TSCi) Working Group, noted the key role of the member organizations of TSCi in working with the international medical community for the development of the new guidelines, and for their publication in a publically accessible online journal. “This is one of the most important contributions TSCi has made to advocating for improvements in patient care worldwide, demonstrating some of the key results of cooperation between TSC patient organizations and TSC researchers. It is an accomplishment the patient community can be very proud of.”